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ABSTRACT

This manual is intended for parents of high school students with severe disabilities and offers guidelines for evaluating a high school program and ways parents can improve existing programs. In the first section seven key characteristics of a good high school are identified: (1) integrated; (2) age appropriate; (3) community-based; (4) future-oriented; (5) comprehensive; (6) parent involving; and (7) effective. For each characteristic, a brief explanation is provided with a rationale and a list of indicators on which to judge the program. In the second section three areas of parent collaboration with the school are discussed. They are: the IEP (Individualized Education Program) process, transition planning, and monitoring and advocacy. Parent involvement in these three areas requires preparation for the IEP meeting and followup with home, school, and community goals; participation in development of the Individual Transition Plan; and ongoing parental monitoring of service quality of the various agencies serving the young adult. (DB)

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PARENT PRIMER

Secondary Programs for Students with Severe Disabilities

Parents' Graduation Alliance
Specialized Training Program
1988

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PARENT PRIMER

Secondary Programs for Students with Severe Disabilities

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Introduction

The Parents' Graduation Alliance has prepared this primer specifically for parents of high school students with severe disabilities. It focuses on those features that you, as a parent, should expect to find in a top quality high school program. Should all or some of those features be missing, the primer also suggests ways that you and other parents can help to establish them in your local school. The basic assumption underlying all of this is that parents are a unique source of information about their children: You know your son or daughter better than anyone.

The adolescent years can be a stressful period for both teens and their families. There is a shift toward an adult orientation as teenagers experiment with growing abilities, independence, and responsibility. This stage in life may be even more complicated and difficult for the teen with severe disabilities. Whether high school students are disabled or not, though, this personal drama of emerging adulthood takes place in school at the same time it is unfolding at home.

There is a growing recognition that many of our schools inadequately prepare students for their transition from school to work and adult life. Thus, special education must face its own version of transition. High school students with severe disabilities require curriculum models and instructional materials specifically designed for their abilities and needs, and aimed toward the most rewarding adult life possible.

You have a vital role to play in planning your child's education during these high school years. We hope this short primer will support you in that role. In the pages that follow, we describe a goal of educational excellence and offer practical information on how to achieve that goal in your own child's school program.

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PART I: WHAT PARENTS SHOULD EXPECT

High school and middle school special education programs should have clear goals about what they are trying to accomplish. In general, secondary education for students with severe disabilities should strive to: 1) prepare students to function in adult work and residential environments within their communities, and 2) provide effective transition to those environments.

In the pursuit of these basic goals, schools need to focus on characteristics that make high school programs more relevant to the realities and expectations of adult life. Seven key characteristics are listed below. Although most of these characteristics overlap, each will be discussed separately.

1. High school should be integrated.
2. High school should be age appropriate.
3. High school should be community based.
4. High school should be future oriented.
5. High school should be comprehensive.
6. High school should involve parents.
7. High school should be effective.

1. High School Should Be Integrated

Students with severe disabilities should go to school with students who are not disabled. This does not mean merely being physically present in the same building with other nondisabled students. Integration should occur throughout the school day and in all aspects of school activities. In many cases, with appropriate coordination and support, students with severe disabilities can attend regular classes with nondisabled classmates. Outside of classes, students with disabilities should participate in school assemblies, pep rallies, lunch in the cafeteria, breaks in the halls, and after-school activities along with other students. Nondisabled students might also volunteer to participate in different activities together with disabled students (e.g., as tutors or classroom helpers). The point is that when it comes to relationships among students, familiarity breeds friendship--not contempt. The more familiar non-disabled students become with their fellow students who happen to have severe disablities--and vice versa--the more likely are these classmates to develop the whole range of relationships that are so important to high school life.

> ". . . familiarity breeds friendship--not contempt."

Why Should High Schools Be Integrated?

One of the two basic goals of special education programs is the thorough preparation of students with severe disabilities for their future as adults in the community. Communities have all sorts of people and settings, attitudes and expectations. Therefore, preparing for the greatest possible amount of community integration as an adult requires the greatest possible amount of school integration. Schools offer an excellent opportunity for students with various abilities to learn to interact with their future neighbors, coworkers, and friends.

How Do You Know if the Program Is Adequately Integrated?

Integration is difficult to measure because it can take many forms and be present in varying degrees even within a single school. However, there are some specific things that you can look for to determine if your child's high school program is adequately integrated.

Indicators of Integration

- **Students all participate in daily school routines:**
  - home room
  - lunch times and class breaks
  - same start and end times for school day
- **Students all participate in special school events:**
  - assemblies, pep rallies, graduation ceremonies
  - athletic events, school plays, concerts, etc.
- **Students participate in at least two integrated "elective" classes during the year:**
  - home economics, art, music, sewing, shop, drama, etc.
- **Students participate in selected units of a regular academic class at least once during the school year:**
  - English, social studies, science, etc.
- **Students are all treated as full class members:**
  - similar locker assignments
  - pictures in school yearbook
  - same "ID" cards as other students have
- **Students use the regular school transportation system.**

2. High School Should Be Age Appropriate

Adolescents with severe disabilities require curriculum designs, instructional materials, and teacher skills that are different from those appropriate for younger children. Instruction should include materials and tasks that highlight the similarities--not differences--of secondary age students, with or without disabilities.

Age appropriate programming also requires that the school day and extracurricular activities be similar to those of nonhandicapped students. With increasing age, students should spend proportionately less time in school buildings and more time in work and leisure training in the community. The classroom atmosphere should reinforce the idea that the students are moving toward adulthood. Bulletin boards and other display areas in the classroom should show that this is a place for adolescents and young adults.

"The classroom atmosphere should reinforce the idea that the students are moving toward adulthood."

Why Should High School Be Age Appropriate?

It is inappropriate and stigmatizing for high school programs to rely on instructional tasks and materials that are normally associated with younger children. For example, counting can be taught while setting the table or grocery shopping rather than with pre-school toys such as blocks. Large piece puzzles, stuffed animals, naming colors, and learning letter sounds are all more appropriate in a pre-school or primary education setting.

How Do You Know if the Program Is Age Appropriate?

Issues about age appropriateness arise all the time. It should be an ongoing concern throughout your child's transition years. In some cases, you may have difficulty knowing whether something is "up-to-date" with the current fads and fashions at your child's high school. Nondisabled friends and classmates can help your child fit in, which is another argument for integration.

Age Appropriate Issues

- Your child's classroom should be located in a school with nonhandicapped students of the same age.
- The atmosphere and materials in your child's classroom should b similar to typical high school classrooms.
- Your child's IEP goals should target activities that are normal for someone his or her age. (This does not require that your child perform such activities independently, but that the instruction occurs within the context of typical activities with whatever level of support is necessary.)
- Your child's daily schedule should be similar to his or her nondisabled classmates (e.g., starting and getting out at the same time, same lunch times).
- Your child's extracurricular activities should be similar to those of a typical high school student.

3. High School Should Be Community Based

A community based approach to secondary special education should replace the regular curriculum (language, reading, math, etc.) with activities necessary for adult functioning (work, leisure, community participation, and residential living). In a community based curriculum, there is an emphasis on frequent performance of activities that are common in the community.

Why Should High School Programs Be Community Based?

Once again, the answer is fairly straightforward. If the basic goal is to prepare students for life in the community, then it seems sensible to work with students as much as possible in those community settings. Needs may vary from community to community. For example, students from larger cities may need bus training more than students who expect to always live in a small town. Similarly, it may be less important that your son or daughter be able to print out a grocery list each day in the classroom, than it is for him or her to be able find the items needed in the local supermarket. One student may use pictures, another may use words, or some other system, but the activity should always be geared to the actual stores that exist in your community.

How Do You Know If It Is Community Based?

The most obvious way to know whether your child's program is community based is simply to see how much of the student's time is spent out of the classroom and in the community. Community based programs will have students going shopping, eating in restaurants, riding buses, and doing job training on a regular basis. Equally important, your child will be using those facilities and services that make your specific community unique, or that fit with your family's interests.

Listed on the next page are some specific features to look for.

Features of a Community Based Program

- Your child should have a curriculum catalog that lists current and future leisure/recreation, personal management, and vocational activities specifically selected for him or her.
- If your child is between 12-14 years old, he or she should spend about 15% of the school week in community settings for specific instruction.
- If your child is between 15-17, he or she should spend about 35% of the school week in community settings for specific instruction (sampling two different jobs per year).
- If your child is between 18-21, he or she should spend approximately 50% of the school week in community settings--about 30% of that time in community jobs.
- Your school district policies regarding insurance and travel should support a community based curriculum.
- Your child's class should have a petty cash system available to provide for the needs of community training (public transportation, grocery items for the classroom, fast food restaurant training, etc.)

4. High School Should Be Future Oriented

Schools must look to the future; otherwise, the preparation they offer will be restricted to residential, vocational, and leisure/recreational opportunities currently available. Unfortunately, the services that are currently available in most communities are less than satisfactory. Just because the only employment program in your community is a sheltered workshop does not mean that your child should be trained to work there. Instead, a future oriented program would use your child's transition years not only to develop his or her vocational skills, but to also create vocational options in addition to the workshop. A future orientation should plan for increased opportunities in community living and integrated employment alternatives.

> "...there needs to be a balance of realism and creativity."

Why Should High School Be Future Oriented?

Early and systematic planning by parents, teachers, and case managers is necessary to ensure that students receive the most appropriate and least restrictive post-school options. Instead of always making people with disabilities "fit" whatever happens to be available, programs should plan for expanding the opportunities to fit the individual. That is what individualized programming is all about.

How Do You Know if the Program Is Future Oriented?

As with the other features discussed here, this too is something of a judgment call on your part as parent. Certainly, there needs to be a balance of realism and creativity. Look for a willingness on the part of everyone involved in your child's program to start planning for the day your child leaves school many years before that day arrives. Of course, planning does not guarantee that all of the opportunities you identify as needed will be ready and waiting when your son or daughter graduates. A lack of planning, though, usually means a willingness to accept the status quo. The items below simply highlight the importance of this coordinated planning process in improving the status quo.

How to Plan for the Future

- The special education program serving your child should have a ***transition manual*** to follow. The manual should be available to you. [An example of such a manual is available from the Parents Graduation Alliance.]

- If your child is over 18, then case managers and adult service providers should attend the Individualized Education Plan (IEP) meetings.

- By the time your child is 18, he or she should have a ***formal transition plan*** in place that is developed with your active participation. This plan should map out what needs to happen in the years prior to graduation for a smooth transition to occur. [A sample transition plan is included at the end of this primer as Attachment A.]

- By the time your child is 18, he or she should probably be registered or entered on all appropriate wait lists for adult services (e.g., residential and vocational services often have such wait lists for programs).

5. High School Should Be Comprehensive

Top quality school programs should have a curriculum and services that cover all of the instructional needs of students with severe disabilities. Moreover, this comprehensiveness should not be based on traditional "developmental" curriculum areas, such as "fine motor skills," or "reading readiness." Instead, the comprehensiveness should exist in terms of addressing the total range of demands that your child might face as an adult in the community. The curriculum should cover the instructional needs of students across a variety of activities and settings. These activities may include grocery shopping, banking, using public transportation, etc. (The point is not that the traditional categories such as fine motor, gross motor, communication, are not important, but that they should be incorporated into the functional activities available to a student.)

Why Should High School Be Comprehensive?

If programs are truly community based and future oriented, then they will also need to systematically include all of the areas of adult life as part of their instructional agenda. If students are to be as independent and productive as possible after graduation, they must be competent in many activities and in various settings, not just one or two.

How Do You Know if the Program Is Comprehensive?

You can recognize comprehensiveness in a high school program in two ways. First, a comprehensive program provides functional instruction across all of the domains of life. Second, instruction within those domains is well prioritized for each individual student. Comprehensiveness does not mean that your child's high school program devotes exactly equal amounts of time to all of the domains of life. For example, as your child approaches graduation, vocational training should typically assume a greater amount of his or her school day. At the same time, participation in other areas or domains of life should not totally disappear from your child's school routine (e.g., personal management, leisure/recreation).

Characteristics of a Comprehensive Program

- Your child's IEP objectives should include work, leisure, and personal management activities.
- Meaningful work experiences and community training should be available to all students, regardless of the degree of handicap.
- Your child's IEP objectives should reflect his or her age and interests.

6. High School Should Involve Parents

Part II of this primer discusses aspects of parent involvement in more detail than here. However, we think it is important to also include parent involvement as one of the seven features of quality high schools. Parent involvement is not something schools do "in addition" to good education. Rather, home-school cooperation is an inherent part of the education process itself

For top quality programs, this feature could be reworded to say that "high school should be involved <u>with</u> parents. Adequate parent involvement is not a one way street running <u>from</u> home <u>to</u> school. This feature could be reworded to say that "high school should be involved <u>with</u> parents." Schools should reach out to parents to provide support to families as those families identify their needs. Good parent involvement, then should not be a burden to families (e. g., meaningless meetings to ratify decisions, rather than to participate in the development of the ideas).

> "Adequate parent involvement is not a one way street running <u>from</u> home <u>to</u> school."

Good parent involvement empowers parents and offers parents a variety of roles:

Examples of Parent Involvement

- participation in the development of IEPs
- participation in parent networks
- home-based instruction
- sitting on advisory boards
- participation in program design
- advocacy for improved educational services
- advocacy for increased post-school options

<u>Why Should High Schools Involve Parents</u>?

Schools should value your involvement because you know as much as anyone about your child. Schools should be involved with parents to ensure that their programs and services are truly meeting the needs and preferences of students <u>and</u> their students' families. At the secondary level there are numerous training needs and relatively little educational time. Decisions regarding the

choice of goals, which goal is taught first, the amount of time invested, and the level of performance can depend not so much on logic as on the value judgments of parents and professionals. Your early and informed participation is also necessary for successful transition planning.

How Do You Know if the Program Adequately Involves Parents?

Of course, the easiest way to answer this question is just to ask yourself if you feel adequately involved in your child's program. However, your answer needs to be based on information about what is possible for programs to accomplish in terms of parental participation. The items below reflect the minimum types of school/home cooperation that good programs foster. Additional opportunities for greater involvement should also be available for those parents who want them.

Areas for Parent/Teacher Cooperation

- The school should provide you with information about adult services and the need to plan for smooth transitions.
- The school should tell you about the opportunities available for your involvement.
- Teachers should contact parents at least twice a month (phone calls, home/school visits, open house, etc.)
- You should have the opportunity to participate actively in the IEP process (i.e., not just attending meetings, but helping choose objectives). [See PART II for more details on this.]
- You should have the opportunity to participate in developing a long-range transition plan for your child during her/his last few years of school. [See PART II for more details about this as well.]

7. High School Should Be Effective

This feature may seem obvious, but it needs to be emphasized. The effectiveness of secondary instruction should be measured, not in terms of accumulated knowledge or classroom behavior, but rather in terms of changes in the student's daily performance in residential, vocational, leisure, and community environments. If the outcomes of all this special education for your child do not improve her or his life, then it is not very special. In the final analysis, the excellence of a program is not determined by plans, or procedures, or good intentions, but by the quality of your child's transition from school to work and adult life.

Why Should High School Be Effective?

Simply put: The proof is in the pudding. Effectiveness is a key criterion in any education service. If a program does not provide students with the knowledge and tools they will need, it is not valuable and may even be counterproductive.

How do you know if the program is effective?

The following list has a few, straightforward indications of how to evaluate the effectiveness of your child's high school program.

Indicators of Effectiveness:

- Your child's teacher should regularly monitor and update the content, complexity, duration, and/or setting of the programs.
- Your child should be making progress toward her/his IEP goals.
- The program should result in an improved quality of life outside of the school environment.
- Approximately eighty percent of scheduled teaching time should actually be spent in instruction.
- There should be regular observation of instruction and programs by the teacher's supervisor and parents.

PART II: WHAT PARENTS CAN DO

Since 1975, special education in the United States has operated under the rules and regulations spelled out in an important piece of federal legislation entitled "The Education of All Handicapped Children Act" (PL 94-142). Among other things, the rules of PL 94-142 (you may also see this law referred to as "EHA") require that parents be given the opportunity to participate in the evaluation, placement, and instructional objectives for their handicapped children.

There are, of course, many more ways that you can be involved in the programs that serve your son or daughter. In fact, you and others who work with your child have a shared responsibility to insure that everyone views parent involvement as something that is important for the success of your child.

In this part of the primer, we will discuss three areas of parent collaboration with the schools. We will examine each of these separately. They are:

1) The IEP process
2) Transition planning
3) Monitoring and advocacy

1. The IEP Process

The Individualized Education Plan (IEP) is the mechanism mandated by PL 94-142 to design a program uniquely suited to the needs of each individual student in special education. The outcome of the yearly IEP process is a written document that spells out a student's educational objectives and the services he or she is about to receive in the coming year. This written plan should be cooperatively developed by the parents, school personnel, and the student. There are three major phases in the IEP process: 1) Preparation for the IEP meeting; 2) the IEP meeting itself; and, 3) follow-up of home, school, and community goals.

> ". . . you do not have to wait for an invitation to initiate your involvement."

Preparation for the IEP Meeting

You and the school personnel are responsible for recommending educational goals for the IEP. Parents sometimes think that it is easier or better to let the teacher make the decisions as to what their son or daughter should learn. The problems with this are, first, that it diminishes your control over your child's education, and second, it may deprive the teacher of the valuable information you possess about your child. Remember, you know your child as well as anyone, and that knowledge is the key to developing a good IEP. As a parent, then, you should be one of the primary participants in the preparation of your child's IEP. This does not mean that you have to become an educational "expert." It is the teacher's job (along with other specialists) to plan the details of your child's program. However, you can help set the basic outline and focus of that program so that it reflects your choices about what is most important for your child. In many cases your child's teacher will welcome your participation, but you do not have to wait for an invitation to initiate your involvement.

Prior to the IEP meeting, you should become familiar with the local curriculum "catalog" and be prepared to suggest goals for your daughter or son from each of the curriculum areas vocational, personal management, and leisure/recreation. The school personnel should review the catalog and recommend goals for each student based on his or her current level of performance. If the school does not have a curriculum catalog (or something similar that lists and describes activities needed for adult life in the community), then you should insist that one be developed. See page 6 for a further description of a community based curriculum.

It is important for you to think about your suggestions ahead of time, and to thoroughly consider your child's preferences as well as your own in regard to specific decisions. In many districts parents and teachers will meet one or more times before the formal IEP meeting to discuss everyone's ideas about activities and goals. This allows you to attend the formal meeting with much confidence about what you want and what others at the meeting will say. If your child's teacher does not mention such preparatory sessions, then you may want to suggest them.

> "It is important for you to . . . thoroughly consider your child's preferences. . ."

The IEP Meeting

With careful preparation you can approach the next step in the process, the IEP meeting, confident that you can express clear preferences for the design of your son's or daughter's program for the coming year. You, school personnel, and your child (if appropriate) should negotiate and select a list of instructional objectives to guide the design of the actual activities and schedule during the next year. These objectives should specifically describe the things your child will do and accomplish. These objectives should then be prioritized, identifying which are the most important, which are less important, and so on. Finally, strategies for accomplishing these goals are determined after considering your child's learning rate and style, the opportunities in the community, and any special strengths of the program or school.

One of the factors that you should make sure everyone thinks about when selecting and prioritizing objectives is the time your child has left in school. In elementary school, there was time to wait and see, to try different approaches to various content areas. With only a few years left of high school, there are fewer objectives a student can still achieve. Often there are trade-offs that have to be considered. For example, the importance of working on job skills may leave less time to work on swimming skills. Work on reading skills may need to focus on certain functional words that your child will need to recognize at work or in the commu-nity. Decisions regarding which task to teach first, the amount of time to invest, and the level of performance can be made only on the basis of value judgments by teachers, parents, and students.

There are other decisions that will need to be formalized at the IEP meeting. Decisions about adaptive equipment can have an effect on the opportunities your child will have to participate in activities that might otherwise be unavailable to them. This equipment can range from sophis-ticated communication equipment to simple teacher-made materials. Another set of decisions to be made at the IEP meeting concerns the desired degree of competence that you want your child to reach in each selected activity. For example, will the grocery shopping goal include learning to shop for all possible items in many stores or will it be limited to a few items at stores within the stu-dent's neighbor-hood? The IEP meeting is the time and place for everyone involved with your child's education to con-sider these decisions and alterna-tives.

Following-Up Home, School, and Com-unity Goals

IEP goals are selected for the home, the school, and community environments. Although you should play a strong role in determining all of the annual goals for your child, your involvement in the area of home goals is particularly important.

Some of the activities selected for your child's school program, such as cooking, cleaning, personal hygiene, yardwork, and leisure activities, can be practiced at home as they naturally occur in the daily family schedule or routine. You can identify those activities, or parts of activities, that you and your

as cooking, cleaning, personal hygiene, yardwork, and leisure activities, can be practiced at home as they naturally occur in the daily family schedule or routine. You can identify those activities, or parts of activities, that you and your family are already doing which offer opportunities for your child to practice and apply what he or she is working on in school. In other cases you may be able to include community training routines into your weekly activities: take your child with you to help do the shopping; have your child help with the yardwork around the house; attend a football game together.

Finally, you may also look for home chores that could be shared with the school as part of your child's education program: send the teacher a list of grocery items and money to use when your child works on shopping; tell the teacher what types of clothes your child could buy at the local department store.

Some of your child's target activities may occur only in the home environment. For example, making one's bed is a chore that needs to be done every day in most homes. It does not occur in a typical school routine. Instead of creating an artificial opportunity to practice "bed-making" in a high school classroom, your child's teacher can help you set up a routine to work on that activity at home without unduly disrupting your normal schedule. Using the school staff for advice, you can gradually increase your child's ability to do the task with more and more independence.

> "The opportunity to rehearse these activities again and again is especially important . . ."

Obviously, the existence of these activities and opportunities in the home is one of the things you consider in preparing your child's IEP. For instance, if you do not want your child helping with yardwork, or you do not have a yard in the first place, then it probably should not appear as an objective on the IEP. Instead, you may identify other home activities that would be more appropriate: for example, preparing breakfast, vacuuming, setting the table, washing windows, or doing dishes.

Typically, as children mature into adolescence, a change in lifestyle occurs. There is a gradual

shift to more responsibility as well as to a wider range of permissible options. You can foster this process by allowing your daughter or son to take more responsibility for personal and household management activities. You and the teachers can work closely together to provide opportunities for practicing all sorts of activities that will be important to your child when he or she leaves the educational system. The opportunity to rehearse these activities again and again is especially important for students with severe handicaps

> ". . .regular contact between home and school is the final stage of the IEP process. . ."

Through frequent, regular communication with your child's teacher you can keep each other up-to-date on how your child's skill in a particular activity is progressing. You can tell the teacher what new skills or problems are emerging at home, and the teacher can share similar information about events at school. On this basis you and the teacher can discuss adjustments to your child's daily routines or expectations. This process of regular contact between home and school is the final stage of the IEP process and helps insure its relevance throughout the school year.

Listed below are some examples of how you, as a parent, might help establish effective home/school collaboration. Examples of home/school collaboration are:

Examples of Home/School Collaboration

Supporting the training provided during the school day.

- On a regular basis, send money and a list of grocery items for your teenager to purchase.
- Provide money for community leisure/recreation training such as swimming at the YMCA.
- Give the teacher recipes that your child could prepare at home after he or she receives training.
- Provide the teacher with a list of home or community activities that you would like your daughter or son to learn.

Examples of Home/School Collaboration (continued)

Providing opportunities outside of the school day to practice targeted activities.

- **Encourage and support your child in preparing his or her own breakfast or sack lunch.**
- **Have your child practice the parts of grocery shopping that he or she is working on at school, or send your child alone to the store if she or he has learned to shop independently.**
- **Provide opportunities for your child to participate in community leisure activities such as swimming at the public pool, playing video games, or just "hanging out" with their friends in town.**
- **Assign household and yard chores to your child and expect them to be completed on a regular basis.**

2. Transition Planning

Basically, the goal of transition planning is to provide the best achievable lifestyle for students when they leave the school system. This planning requires a set of decisions related to where students will work, where they will live, and what type of leisure or social activities they will engage in when they are no longer in school.

No single program in the adult service system will provide all the opportunities that parents might desire for their son or daughter. You will have to choose the type of activities or the services that are <u>most</u> important to you, and then add services or family resources to that program. For example, when considering day programs, you may be forced to choose between a program that focuses on preparation for work and one which stresses real work and wages. You might also face a choice between a part-time job with high wages or placement in a full day program where wages are extremely low. In one family, a part-time job in which the son or daughter with severe disabilities would be home each morning might be quite feasible. In another family, in which both parents work and no one is home during the day, the same job could present difficulties. In some situations parents may have little real choice. There may be only one program available and parents are told simply to "take it or leave it."

> ". . . some transition planning should begin as soon as the student enters a high school program."

For all of these reasons, one statement about transition planning cannot be emphasized enough. **Transition planning should be undertaken with great care and should not be put off until a student's final year in school.** In fact, some transition planning should begin as soon as the student enters a high school program. In particular, you should begin quite early to identify the gaps and opportunities in adult services in your community and work to improve them by the time your child leaves school.

The Individual Transition Plan

An individual transition plan is similar to an IEP. It is a written document that describes goals and objectives for your son or daughter -- the specific programs and services needed to accomplish those goals and objectives. However, a good transition plan will cover a longer span of time and take a broader scope than the typical IEP. In general, the transition plan will depend on three broad factors:

1) Family values (i.e., the relative importance of work success and wages, integration, etc.)

2) Quality and availability of local services.

3) Family resources (e.g., time or money to supplement these services).

[Note: A general guide to transition planning is presented in Figure 1.]

The transition plan should be a formal written document with goals that stress the productivity, community participation, and independence of students leaving the school system. Parents should assume the role of informed consumer and ultimate decision-maker in this transition process. School personnel are responsible for providing effective preparation for post-school life, and the adult service providers function as advisors in this effort. In most cases, a designated "case manager" (this person might be called something different in your state) will probably be the primary representative of the adult service system in the transition planning process. This person should provide enough information about community service options so that both you and the teacher can adequately plan for your child's transition.

> "Parents should assume the role of . . . ultimate decision-maker in this transition process."

Components of the Transition Plan

When a student turns 18, the case manager should begin to attend your child's IEP meetings. The case manager must become familiar with your child's needs and abilities in order to plan for his or her entry into the adult service system. The case manager should also provide information on adult services so parents and teachers can prepare for these options. Planning for transition should begin <u>at least</u> two years prior to the student's graduation. A transition plan should identify

Figure 1
Transition Checklist

Age of Student	Action	How to Initiate
16	1. Obtain copy of transition manual	Contact classroom teacher
16	2. Attend district or ESD parent meeting on transition planning	
16	3. Obtain Social Security Number	Call Social Security Office*
17	4. Apply for entitlement programs: ___ Supplemental Security Income (SSI) ___ Medical Assistance (Medicaide) ___ Other	
18	5. Make application to MR/DD program office of the Mental Health Division	
18	6. Visit potential work sites	Contact MR/DD Casemanager*
18	7. Visit potential residential placements	Contact MR/DD Casemanager*
18	8. Develop long term plan for financial support and advocacy	Contract ESD/LEA transition coordinator Contact GAPS Program*
18	9. Invite MR/DD casemanager to IEP meeting	Contact MR/DD casemanager*
20**	10. Develop transition plan	Contact transition coordinator Contact MR/DD casemanager*
20**	11. Apply for Mental Health residential program	
20**	12. Apply for day program: ___ Mental Health Division ___ Vocational Rehabilitation ___ Other	
21	13. Placement at graduation	
22	14. Follow-up	
	15. Other	

** These times are only approximate. Planning may have to occur even earlier depending on the length of local waiting lists and/or the severity of a student's handicap.

needed services, responsibilities, and timelines in the major areas that will affect the student's life in the community. While the importance of any one issue will naturally vary from student to student, you should ensure that at least the following components are addressed in your son's or daughter's transition plan.

1. A specific vocational option.
   Vocational preparation is training for a particular job or job type while in school that will be available in the community immediately after graduation. You should participate in the job selection and monitor your child's program to ensure that comprehensive on-the-job training takes place prior to leaving school.

2. A residential option.
   You should also begin to plan a specific living arrangement for your son or daughter. If local residential service providers have particular requirements for their residents, or if the home environment demands certain skills, these should be understood and anticipated. A stable arrangement for job and home is a crucial foundation for a successful community life.

3. Appropriate leisure activities and services.
   The quality and quantity of leisure activities make an important contribution to a person's lifestyle. For this reason, you should identify appropriate leisure options that your child and family enjoy, and then plan continued access to these activities.

4. Long term care.
   Transition planning should include considerations for the welfare of your child in the event of your death. The designation of an advocate or guardian and specific plans for financial care through your will or trust fund are some of the steps you may want to take. In most states, the Association for Retarded Citizens (ARC), can refer you to experienced lawyers and others who can provide valuable information in this area.

5. Family involvement and support. The transition plan should identify the responsibilities of family members and other significant people.

6. Income support. Arrangements should be made to apply for entitlement and eligibility programs for which the student will qualify. The MR/DD case manager is the person who helps to make these arrangements.

7. Transportation. Planning for transportation to work and leisure activities should be considered. Is there a public bus system that is accessible? Has your son or daughter learned to use it?

8. Insurance/Medical Needs. If a student is eligible for SSI payments upon turning 18, her or she is also eligible for Medicaid coverage. This program pays for physicians' costs, prescriptions, dental care, glasses, and a variety of other medical needs. In some states there may be additional health care programs available to children with disabilities under the age of 18.

Your child's transition plan should identify the agencies that can best provide these services and should include adequate directions about how to obtain the services and benefits of these agencies. Teachers and case managers are responsible for providing pertinent details about the services, which should be noted in the plan. A sample Transition Plan can be found in the Attachments.

3. Monitoring and Advocacy

Monitoring

Parents are required to complete the applications for various local, state, and federal benefit and service programs. This can include vocational, residential, and medical and income support programs. Once appropriate services are secured, the major task for you is to help maintain and evaluate those services. This involves monitoring service delivery and documenting any changes in services. You should keep careful records of contacts and correspondence with service providers. Such records are important in adding or reinstating needed services. The following are suggestions for you to refer to as you monitor the programs available for your child.

1. Coordination among agencies. Parents should emphasize the need for school districts and adult service programs to work together to plan and coordinate resources. Schools should be aware of the services that will be available to future graduates, so that adequate vocational preparation can occur. Adult service agencies need information concerning the number of graduates and their needs in order to plan for future services.

2. Information on service options. Parents need information to plan. You should request that schools and adult service agencies develop cooperative information systems so they can more easily share information with you. This information could be provided through training sessions, transition manuals, or presentations to parent support groups.

3. Maintain regular records of the outcomes achieved. Parents should monitor the wages earned in employment, the activities offered in residential programs and other program outcomes. You should request overall program results (for instance, worker's wages) and compare them to the results of other programs, and to the benefits derived by your son or daughter.

4. Request information on progress through training programs. Students and graduates should always be

receiving training. You should expect regular data from teachers, employers, and residential staff on this training progress, and not simple reports or stories about your son's or daughter's performance. One method to do this is through the planning and preparation of annual plans similar to the IEPs your son or daughter had in school. In Oregon these are called Individual Service Plans (or ISP). In other states they are called different things (e. g., Individual Habilitation or Treatment Plans). Whatever they are called, these outlines of adult service objectives must be ongoing to provide individuals with disabilities the opportunities to learn new jobs, earn more money, work, and live in integrated environments, enhance personal security, and so on.

5. Keep an eye on the quality of services. Funding and regulation of service programs is often complicated and confusing. It pays to keep a sharp focus on the quality of the services your child is receiving. A good program can quickly become mediocre or worse if the persons using the services, their families, and advocates do not take an active interest in program quality. Perhaps the best way to measure quality is to examine the benefits your child receives from the services. Below is a partial list of "quality" questions you should ask on a regular basis. These questions may best be answered by your child, a service provider, or yourself through direct personal observation.

> "It pays to keep a sharp focus on the quality of the services your child is receiving."

Questions Regarding Job Quality

- Does your child seem to like his/her job?
- How much money did your child make this month?
- How do his/her wages compare to the average wage of other workers in the program?
- How do they compare to the average wages of workers in other programs?

- Is the amount of work available likely to increase or decrease?
- If your child is working less than full time, could his/her hours increase?
- Is the work meaningful and socially valued?
- Does your child have daily opportunities to interact with coworkers without disabilities?
- Is your child making friends through work?

Questions Regarding Home Quality

- Does your child seem to like where he/she lives?
- Is your child learning to do things for him/herself?
- How often does your child get to do social or recreational activities outside of the home environment?
- Does he/she socialize or recreate regularly with persons other than roommates and paid care givers?
- Is the amount of staff support sufficient?
- Has there recently been a lot of changeover in staff?
- Is the residence clean, homey, free of hazards, i.e., a place you yourself might choose to live?

At the very least, parents should keep abreast of any plans to begin new local programs. This will allow you to plan a possible program change for your son or daughter.

Advocacy

Individuals with disabilities must be provided a free and appropriate education. They are not, however, entitled to adult services such as jobs. These individuals will often depend on family members for support needed to gain or maintain employment. Needed family assistance may include arranging or providing transportation, advocating improvements in existing services, and identifying more appropriate service alternatives. An excellent way for you to influence the overall quality of services for all adults with disabilities is to become a member of the board of directors of a service provider agency or a county mental health advisory committee.

Advocacy Programs.

In most states there should be at least two organizations available for support and advocacy. One is the state Protection and Advocacy agency. Every state is required to have one of these agencies for the specific purpose of providing legal and technical assistance to individuals with developmental disabilities and their families. In Oregon the agency is called The Oregon Advocacy Center (OAC), and has its offices in Portand. A second type of advocacy organization that has chapters in every state is the Association for Retarded Citizens (ARC). The ARC is a national parent organization focused specifically on issues affecting people with mental retardation. The state offices for the ARC of Oregon are located in Salem; local chapters are located throughout the State. There may very well be additional advocacy organizations in your state or community. Do not limit your search to disability organizations, either. Many of the problems that people with disabilities face are shared by other people in our society who for whatever reason face discrimination and inadequate services in response to their needs.

Parent Programs.

Finally, one avenue for additional advocacy and information is through the formation of locally based parent networks specifically focused on issues of transition and adult services for individuals with severe disabilities. Such a network has proven useful in Oregon. The Parents Graduation Alliance (PGA) is a statewide network of local parent teams all of whom work together to accomplish the common goal of smooth transitions between effective school and post-school service programs. For additional information about the PGA, its structure and function, please contact us at the address below.

Roz Slovic, Project Coordinator
Parents' Graduation Alliance
Specialized Training Program
135 Education
University of Oregon
Eugene, OR 97403
(503) 686-5311

ATTACHMENTS

LANE EDUCATION SERVICE DISTRICT

INDIVIDUAL TRANSITION PLAN

Student's Name Ed

High School South Eugene High School

Date of Birth May 25, 1966

Date of Graduation June, 1987

Social Security

Selective Service

Date #1 May 27, 1985

Participants Ed W., Anita C., Connie J., Allan T., Glenda T.

Date #2 May 31, 1986

Participants Ed W., Anita C., Connie J., Allan T., Glenda T., Jeanne H.

Date #3

Participants

ACTION	OUTCOME	ACTION	OUTCOME
1) Copy of transition manual given to parents	May 27, 1985	6) Transition plan developed	May 31, 1986 take update, as necessary
2) Entitlements applied for: ___ Social Security Insurance ___ Medical ___ Other	parents will apply June, 1986	7) I.E.P., Psychological Evaluation and Transition Plan sent to Mental Health	May, 1986 discussed at IEP meeting
3) Long-term guardianship and financial plan developed	pending further discussion	8) Placement at graduation Vocational: Residential:	 wait list wait list
4) Mental health invited to IEP meetings	Casemanager attends all IEP meetings	9) Follow-up	
5) Applied Mental Health for Vocational program: Residential:	 June, 1986 June, 1986	10) Other	

Income/Financial Support/Life Insurance

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Ed is currently receiving SSI benefits. The check will be transferred to the appropriate person when final residential placement decisions are made.	Anita will arrange for the check transfer from Ed's father to herself or Glenda Timmons.	June 10			Alan will confirm transfer	July 15

Long-Term Support/Will/Guardianship

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
The implications of a trust on entitlements was discussed. Action has not yet been taken in this area.	Anita will contact GAPs program	July 1	Connie will provide Anita with telephone # and contact person for GAPs program.	June 15		
Ed is his own legal guardian. Advocacy will be a collaborative effort on the part of Allan Taylor, the residential care provider, the vocational staff, & the parents.					Allan will notify Anita of semi-annual IHP review.	As needed
Action has not been taken in this area.	Anita will contact GAPs program.	July 1				

Medical Insurance/Medical Needs

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Ed is currently taking Dilantin and Mycelin. Ed had an EEG last month and is scheduled to have another one in Aug.					Allan Taylor will send a copy of Ed's medical records to LCC.	June 7
Ed has a medical card that will cover these expenses.						

Transportation Skills/Needs

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Ed will use the city bus to get to work and community events.					LCC staff will begin bus training to and from work as soon as Ed's living	July 1
					arrangement is settled.	

Vocational Skills/Preferences/Needs/Placement

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Ed will begin a 30-day evaluation period at LCC the second week in June. Ed will remain on the D.P.S. waiting list for the time being.	Anita will provide LCC a doctor's verification that Ed has had a physical examination within the past year.	Prior to the 2nd wk. of June	Connie will be responsible for sending copies of Ed's IEPs for the past 2 years, progress reports and medical records to LCC.	As soon as possible	Jeanie Hart will make arrangements for Ed to start at LCC.	June 30

Residential Placement and Maintenance of Family Relationship

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Ed has visited the prospective foster home and expressed an interest in living there.					Allan Taylor will make arrangements for Ed to spend a weekend at Glenda	July 3(
Ed will spend a weekend with Glenda Timmons family before a final placement decision is made.					Timmons by 6/2.	
Ed will remain on the Alvord Taylor waiting list until an opening occurs.						

Community Leisure Options

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Glenda Timmons will check on Parks and Recreation summer schedule.					Allan will assist Glenda to register Ed for Parks & Recreation.	July 1

Personal Management Needs

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line
Ed will have access to a mall and deli or needs to bring a sack lunch.	Parents will provide the opportunity for Ed to make lunch once a week.		Connie will continue training of showering after PE. Will provide copies of	June 10		
			personal management prosthetics.			

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

LANE EDUCATION SERVICE DISTRICT

INDIVIDUAL TRANSITION PLAN

Student's Name _____ Date #1 _____

High School _____ Participants _____

Date of Birth _____ Date #2 _____

Date of Graduation _____ Participants _____

Social Security _____ Date #3 _____

Selective Service _____ Participants _____

ACTION	OUTCOME	ACTION	OUTCOME
1) Copy of transition manual given to parents		6) Transition plan developed	
2) Entitlements applied for: ___ Social Security Insurance ___ Medical ___ Other		7) I.E.P., Psychological Evaluation and Transition Plan sent to Mental Health	
3) Long-term guardianship and financial plan developed		8) Placement at graduation Vocational: Residential:	
4) Mental health invited to IEP meetings		9) Follow-up	
5) Applied Mental Health for Vocational program:		10) Other	

Income/Financial Support/Life Insurance

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Long-Term Support/Will/Guardianship

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Medical Insurance/Medical Needs

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Transportation Skills/Needs

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Vocational Skills/Preferences/Needs/Placement

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Residential Placement and Maintenance of Family Relationship

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Community Leisure Options

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Personal Management Needs

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Comments/Recommendations	Responsibilities					
	Parent/Guardian		School		Adult Service Prov.	
	Action	Time Line	Action	Time Line	Action	Time Line

Parent Primer
Secondary Programs for Students
with Severe Disabilities

Evaluation Form

I am a parent ____, teacher ____, other _____.

Please rate each part of the Primer by circling the appropriate number on the scale.

Part I: What parents should expect

		Low				High
1.	Accuracy of content	1	2	3	4	5
2.	Usefulness of content	1	2	3	4	5
3.	Clarity of content	1	2	3	4	5
4.	Organization of content	1	2	3	4	5

Part II: Parental involvement

1.	Accuracy of content	1	2	3	4	5
2.	Usefulness of content	1	2	3	4	5
3.	Clarity of content	1	2	3	4	5
4.	Organization of content	1	2	3	4	5

Attachments

1.	Usefulness of forms	1	2	3	4	5
2.	Design and clarity of forms	1	2	3	4	5

Overall satisfaction with Primer		1	2	3	4	5

Did you revise or adapt any parts of this manual? yes ___ no ___

If yes, please explain:_____

_____

_____

How did you use this manual? (Check all responses that apply):
Read ____; Used forms ____; Shared with others ___; Used in training ___.

We plan to periodically revise and update the Parent Primer. On the back of this form, please write your **comments and suggestions** on how we might improve this manual.

Thank you for completing this evaluation. Please return it to:

Roz Slovic, Project Coordinator
Parents' Graduation Alliance
135 Education, University of Oregon
Eugene, Oregon 97403

PGA:EvalPrimer